

One Hundred Seventh Congress of the United States of America

AT THE FIRST SESSION

*Begun and held at the City of Washington on Wednesday,
the third day of January, two thousand and one*

Concurrent Resolution

Whereas at least two children born each day will be affected with tuberous sclerosis;

Whereas nearly one million people worldwide are known to have tuberous sclerosis;

Whereas tuberous sclerosis affects all races and ethnic groups equally;

Whereas tuberous sclerosis is caused by either an inherited autosomal disorder or by a spontaneous genetic mutation;

Whereas when tuberous sclerosis is genetically transmitted as an autosomal dominant disorder, a child with a parent with the gene will have a 50-percent chance of inheriting the disease;

Whereas two-thirds of the cases of tuberous sclerosis are believed to be a result of spontaneous mutation, although the cause of such mutations is a mystery;

Whereas diagnosis takes an average of 90 days with consultation of at least three specialists;

Whereas tuberous sclerosis frequently goes undiagnosed because of the obscurity of the disease and the mild form the symptoms may take; and

Whereas the Congress as an institution, and Members of Congress as individuals, are in unique positions to help raise public awareness about the need for increased funding for research, detection, and treatment of tuberous sclerosis and to support the fight against tuberous sclerosis: Now, therefore, be it

Resolved by the House of Representatives (the Senate concurring), That it is the sense of the Congress that—

(1) all Americans should take an active role in the fight against tuberous sclerosis by all means available to them, including early and complete clinical testing and investigating family histories;

(2) the role played by national and community organizations and health care providers in promoting awareness of the importance of early diagnosis, testing, and ongoing screening should be recognized and applauded;

(3) the Federal Government has a responsibility to—

(A) endeavor to raise awareness about the importance of the early detection of, and proper treatment for, tuberous sclerosis;

(B) increase funding for research so that the causes of, and improved treatment for, tuberous sclerosis may be discovered; and

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(C) continue to consider ways to improve access to, and the quality of, health care services for detecting and treating tuberous sclerosis; and

(4) the Director of the National Institutes of Health should take a leadership role in the fight against tuberous sclerosis by acting with appropriate offices within the National Institutes of Health to provide to the Congress a five-year research plan for tuberous sclerosis.

Attest:

Clerk of the House of Representatives.

Attest:

Secretary of the Senate.